



AUGUST 2013

# EHDI E-MAIL EXPRESS

The monthly newsletter of Early Hearing Detection and Intervention Program

This is an e-mail communication from the American Academy of Pediatrics (AAP) "Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home" project funded through cooperative agreements with the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), National Center of Birth Defects and Developmental Disabilities (NCBDDD). It is designed to provide AAP Early Hearing Detection and Intervention (EHDI) Chapter Champions with resources and current clinical and other information. The EHDI E-Mail Express is sent on a monthly basis. Please feel free to share the EHDI E-Mail Express with colleagues working on or interested in childhood hearing detection and intervention issues. Distribution information appears on the last page.

In this issue:

- Message from your Chairperson
- Upcoming Events
- Hearing Loss and Bullying
- Association of Family History and Consanguinity with Permanent Hearing Impairment
- The Clinical and Audiologic Features of Hearing Loss Due to Mitochondrial Mutations
- The Power of a Written Result: Nevada Sees Improved Hearing Screening of Infants
- Champion Work Plans
- Words of Inspiration

## FROM YOUR CHAIRPERSON



Technology can be an amazing thing...

I find myself thinking about technology this week, in part because I just spent fourteen days without any. I had the good fortune this summer to float on a raft trip down the Colorado River, traveling on the river from one end of Grand Canyon National Park to the other. Fourteen days with no cell phone, no internet, no contact with work or family, just daylight hours spent on the river or hiking the canyons, and nights spent under the stars. Conversation over dinner, yes, a few sing-along tunes played on an undersized guitar perhaps, but no television or radio. A few letters were written during the trip... not today's version of electronic letters, but the old-fashioned kind that must be folded into an envelope and sent with a stamp. It was easy, I discovered... at least for me. And not quite so easy, it turns out, returning to my technology-filled world.

Still, as I type this out on a word processor, I find myself realizing that technology can be a wonderful thing. Technology has helped those of us in the EHDI world transition from performing newborn hearing assessments with noisemakers and "distraction" testing to screening with computerized brainstem and auditory nerve assessments. Technology has offered improvements and miniaturization in hearing aid technology for infants born hard of hearing. Technology has offered improving generations of cochlear implants for families who might choose that intervention for the deaf newborn. Technology has offered instant communications for those who are deaf through texting, and has offered an interface between the deaf community and the hearing community through videophone interpreter connections and the like. And technology has allowed for providing audiology and speech therapy services from a distance, through advances in telemedicine.

I was intrigued recently to hear a story on National Public Radio about the development of an electronic retina for patients with one form of blindness, retinitis pigmentosa. The technology seemed relatively primitive to my thinking, allowing only the distinction of light and dark shadows, but it nevertheless proved helpful enough to protect the individual from injury and to manage some activities of daily living. I couldn't help thinking about the evolution of our common EHDI technologies and the rapid advancements we have seen in our own field. Will the electronic retina show increasing promise in a few short years? It seems likely, I would think.

We have seen technology advance dramatically over the last few decades. That might seem frustratingly slow if it has coincided with a full career of working in the field. But I prefer to think of the changes as incredibly fast, wonderfully fast, almost too fast to stay abreast and stay current with the changes that are evolving.

The rocks in the very bottom of the Grand Canyon, I learned this month, are some 2 billion years old. And our work in the EHDI arena, in comparison, is a blink of the eye.

Thanks for being part of the wild ride. Hold on... things won't be slowing down any time soon!

- Al

## UPCOMING EVENTS

Event	Date	Location	Details
Genetics and Hearing Loss for EHDI Professionals	September 9 – 15, 2013	Gallaudet University, Online Course	<a href="#">Web site</a>
AAP National Conference and Exhibition	October 26-29, 2013	Orlando, FL	<a href="#">Web site</a>

## HEARING LOSS AND BULLYING

Bullying is a serious and increasing problem in many United States schools with approximately 30 percent of students in grades 6-10 having been involved in some type of a bullying incident (Coloroso, 2004). Children with observable disabilities—such as hearing aids, cochlear implants, etc—may be twice as likely to be targets of bullying although there is no specific data yet to confirm that (Sullivan, 2006).

As an advocate for children who are deaf or hard of hearing, there are several signs of bullying to be aware of including:

- Refusal to go to school or sudden lack of interest in school.
- Change in grades.
- No longer shows interest in family or school activities.
- Appears sad or angry after a phone call/text message/email.
- Does or says something that is out of character.



Getting children to open up about bullying can be difficult but it is important to encourage them to do so. Take what they are saying seriously and be prepared to address their concerns. Teach children how to build friendships and how to identify “real” friends. Additionally, educate children about appropriate and timely responses when faced with by a bully.

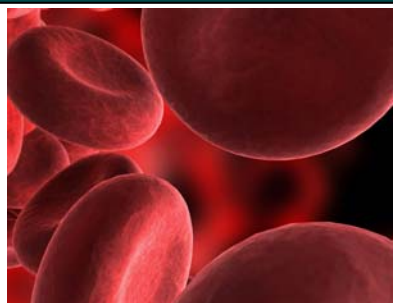
Learn more about how to identify children who are being bullied and ways to help them overcome it by reading the full Alexander Graham Bell (AG Bell) August e-Newsletter article at: <http://www.listeningandspokenlanguage.org/Document.aspx?id=1191>.

## ASSOCIATION OF FAMILY HISTORY AND CONSANGUINITY WITH PERMANENT HEARING

A new study *Association of Family History and Consanguinity with Permanent Hearing Impairment* in the *Indian Journal of Otology* finds family history and consanguinity are strongly associated with congenital permanent hearing impairment. Since a child with family history is six times more likely to have permanent hearing impairment the study aimed to find the strength of this association. It was a case-controlled study of 420 children between the ages of 6 months to 2 years with permanent hearing impairment and normal hearing born in the years 2008–2012. The results indicated that there is a strong association which will be helpful in planning national deafness prevention programs in India.

Source: Selvarajan H, Arunachalam R, Bellur R, et al. Association of Family History and Consanguinity with Permanent Hearing Impairment. *Indian Journal of Otology* 2013; 19:62-65.

## THE CLINICAL AND AUDIOLOGIC FEATURES OF HEARING LOSS DUE TO MITOCHONDRIAL MUTATIONS



The journal *Otolaryngology – Head and Neck Surgery* recently published an article *The Clinical and Audiological Features of Hearing Loss Due to Mitochondrial Mutation* which aimed at characterizing mitochondrial sequence variants present in a nationwide hereditary deafness DNA repository of samples from deaf subjects and to define the clinical presentation and audiometric characteristics of individuals with a mitochondrial sequence variant. This was a retrospective review of results for select mitochondrial mutations performed on DNA samples from subjects compiled from 1997 to 2009. Researchers determined that mitochondrial deafness (in this sample) was associated with a variety of genetic mutations and wide spectrum of clinical presentations.

Source: Yelverton J, Arnos K, Xia X, et al. The Clinical and Audiologic Features of Hearing Loss Due to Mitochondrial Mutations. *Otolaryngology – Head and Neck Surgery* 2013; 148:1017-1022.

## NEVADA SEES IMPROVED HEARING SCREENING OF INFANTS



A recent issue of the National Initiative for Children's Healthcare Quality (NICHQ) e-newsletter featured an article about improvements in hearing screening in the state of Nevada. In an effort to improve the early hearing detection and intervention (EHDI) system, NICHQ has worked with 49 states to enhance processes that will help prevent developmental delays in children with hearing loss. Nevada was highlighted in the newsletter as one state that has seen significant improvement after employing several quality improvement techniques learned through the NICHQ Improving Hearing Screening & Intervention Systems (IHSIS) program.

At the end of 2012, Nevada saw a 28% (going from 77% to 49%) decrease in the number of infants whose hearing diagnosis was unknown by the state in 2011. Some of the changes implemented by the state team—which includes audiologists, parents, and staff from the Nevada EHDI program—included handing out hearing screening certificates, calling families who did not have a record of follow-up after failing the hearing screen, improving communication with audiologists, primary care physicians, and families, and getting infants from audiologists to early intervention services as quickly as possible. With these small changes, Nevada has made big improvements. To learn more visit <http://www.nichq.org/stories/IHSIS-TeamProfile-August2013.html>. And, consider reaching out to the Nevada AAP EHDI Chapter Champion, Cheryl Robinson ([cheryl.r@sbcglobal.net](mailto:cheryl.r@sbcglobal.net)) to learn more.

## CHAMPION WORK PLANS

At this year's annual EHDI meeting, Champions prepared action plans outlining activities that would be carried out over the course of this year based on the specific needs and challenges of his/her state. Many of the activities outlined involve working with other EHDI stakeholders in the state including state EHDI coordinators, audiologists, and physician colleagues. We hope you have put your work plans into "action" and have been making progress on the activities you identified as priorities! If you have not done so yet, please let us know how we at the American Academy of Pediatrics can help. If you need a copy of your plan, contact Faiza Khan ([fkhan@aap.org](mailto:fkhan@aap.org)). We cannot wait to learn all that you have achieved in the coming months as we will be checking in with you soon!

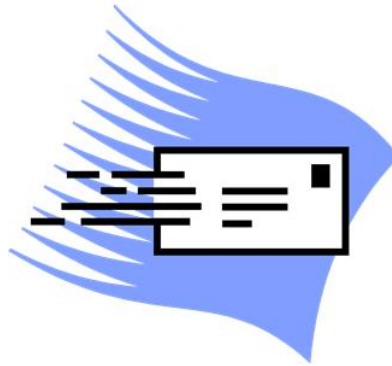


## WORDS OF INSPIRATION...



*The 3 C's of life: Choice, Chance, Change. You must make a choice to take a chance or your life will never change.*

~Anonymous



***Distribution Information:***

*The AAP EHDI Program implementation staff send this e-mail update to the Academy's EHDI Chapter Champions, other interested AAP members, staff and state EHDI coordinators. For additional information on hearing screening and to access previous editions of the EHDI E-mail Express, click on the following link <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>. Previous e-mail updates are available upon request from Faiza Khan, [fkhan@aap.org](mailto:fkhan@aap.org) or (847) 434-4924. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.*